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## Power-full Patient Participation

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## Summary

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Patient participation is a popular concept in the context of health care in the Netherlands. With its origins in the context of the disability movement in the 1960s, patient participation is related to notions of democratic rights for patients, social inclusion, empowerment, self-reliance, involvement and the opportunity of having a voice. Besides these democratic and ethical notions, the experiential knowledge and perspectives of patients on their disabilities and the care they receive is increasingly acknowledged as valuable, because it is assumed that their unique perspective can contribute to a better quality of care and quality of life. Patients have become more involved in the policy making practices in health care organizations and they increasingly participate in health care research. Although the strive for patient participation in theory is often underlined by health care institutions, in everyday practice patient participation seems to be complex and the people involved often have many questions about how to put patient participation into practice. Research on patient participation itself has merely been focused on the added value of participation or on the conditions for involvement. Less attention has been paid to the relational complexity, the way patient participation can evolve and emerge, and how to further open spaces for patient participation in the context of health care practices. Also, the meaning and value of participation for those involved has rarely been studied, because its meaning seems self-evident.

In order to fill this gap and contribute to the emerging literature on patient participation, the aim of this thesis is to learn about, and contribute to the understanding of the complexity of patient participation in health care institutions, and how open spaces for patient participation can emerge. It is an explorative journey through the landscape of participation of patients. At different places in this landscape striving for participation has become visible. We look at these different places where patient participation emerges. At the same time, we do not only want to learn and explore patient participation from an outsider position, we are also part of this landscape. We as researchers also underline the values of patient participation and want to learn in a participatory way; we also “do participation” by using a responsive evaluation approach developed by Abma and her team. We chose this approach because it helps us to understand the meanings of participation from multiple stakeholder perspectives, and to contribute to the personal and mutual understanding of stakeholders through dialogue and participation. Thus, we want to contribute to the emergence of open spaces in health care practices, in which all involved can have a say, from a moral horizon of social inclusion in order to contribute to good care and good life.

The main research question in this thesis is:

*How to further the emergence of open spaces in health care institutions with participatory approaches and what is the importance of such open spaces for patient participation and inclusion?*

To find answers to this central research question we use two guiding sub questions:

*What does patient participation mean to those involved in everyday health care and research practices and how do the different meanings and perspectives of participation interact?*

*What do our findings imply for the further development of responsive evaluation and other participatory research approaches?*

In order to find answers to our research questions, we studied patient participation in diverse health care and research practices. As we describe in the **general introduction** in **chapter 1**, the diverse contexts can be seen as case studies of that specific natural setting, in which the meanings and perspectives (of participation) of all involved was the focus, as well as how the different meanings (of participation) interacted, and how participation amongst all involved emerged. In each of the case studies we used a responsive research design.

Studying patient participation in a participatory way makes this thesis multi-layered and provides an opportunity to explore our questions on different levels: we can learn from the different case studies (different places in the landscape of participation) about the different meanings and perspectives on participation, and how in these diverse contexts the process of patient participation can evolve and emerge. Besides that, we can learn from our own “doing participation” within these practices, when we want to further the emergence of open spaces for patient participation from the moral horizon of inclusion.

This thesis consists of three parts. Part A focuses on case studies that relate to patient participation within the context of patient involvement in policy making processes within health care organizations for long term care, including an organization for elderly care and organizations for people with disabilities. Part B describes a case study of a responsive evaluation study in which the perspectives and experiences of patients (people with aphasia) on participation are explored in the context of rehabilitation health care and support, and in part C we present a case study related to patient participation in the context of research with people with an intellectual disability.

All parts consist of one or more case studies that are published as articles in various journals or as book chapter. Also, they consist of auto-ethnographical reflections. These are about our own experiences and the complexities we encountered ourselves within the specific context, as described in the related case study or studies. The chapters and reflections in this thesis are not presented in chronological order of when we conducted the studies or published our articles. The order is instead guided by what we discovered along the way about the relational complexity of patient participation, and the increasing awareness of our own entanglement and involvement in this complexity. All the auto-ethnographical reflections, in combination with the case studies, offer a fertile ground to learn about patient participation and will help us to find answers to our research questions.

## PART A

The chapters in part A of this thesis focus on patient participation within the context of patient involvement in policy making processes within health care organizations. In the three presented case studies we explore the everyday practice of the collective involvement of patients or clients in client councils. Health care and welfare organizations have a legal obligation to establish a client council in The Netherlands. In theory, this involvement is valued and related to notions of democratic and ethical rights of clients to have a voice and to have the opportunity to be involved in decision making. Also, this involvement is seen as a way to contribute to the improvement of quality of care. In contrast to theory, this everyday practice is more stubborn, as we illustrate in the different studies. Giving form to this process is complex.

In the three chapters of part A we illustrate what happens in everyday practice when professionals in health care organizations try to find ways to include the perspectives and experiential knowledge of patients and clients in policy-making processes within client councils. We also describe our learning experiences with an alternative for client councils, which is based on the notions of responsive evaluation, called the PARTNER approach. This alternative aims to further the emergence of open spaces for the collective involvement of patients within health care organizations; open spaces in which the experiential knowledge and perspectives of patients is valued, and can merge with the perspectives and knowledge of professionals and management. We try to interpret what happens in the everyday practices, by using theory of Habermas and Foucault, in order to contribute to the understanding of patient participation.

In the case study in **chapter 2**, we describe our learning experiences with enhancing the involvement of older people in a residential care home in the Netherlands. We illustrate what happens when we use the PARTNER approach as an alternative for a client council. In our attempt to understand what happens in everyday practice, we use Habermas' theory of system and lifeworld and we use his concept of communicative space. We tried to create a communicative space through dialogue in this study; this can be seen as an open space where all involved can share their perspectives, and where the experiential knowledge of patients and clients is valued. Within this open space, all different perspectives can bring mutual understanding and new insights through dialogue.

In this chapter we bring to the fore that the creation of an open space as such is not an easy task, because within this open space, power issues are at stake. In terms of Habermas: system values like safety and productivity interfere and seem to dominate the lifeworld, and expert knowledge seems to be more valued than expressed emotions and narratives of residents. From our learning experience we derived that researchers who use participatory action research (including ourselves), with the aim of contributing to the emergence of open spaces, must be aware of these issues of power, often hidden in language and discourse. Dialogue can be a vehicle to enhance mutual understanding, when attention is paid to underlying values, assumptions and meanings of all people. But this is a complex process, related to power dynamics.

Chapter 2 is followed by **reflection I**, which is about what I, Susan, encountered when I started working with the responsive evaluation approach. It details what I learned about my own position as a researcher while “doing participation”. I became aware that I cannot do research as an outsider, while

attempting to further the emergence of open spaces for patient participation. It provoked questions about “good participation” and about how to relate to science myself.

In **chapter 3** we present a case study in which we describe the daily practice of a client council of a health care organization for people with intellectual disabilities. Although, in theory, this council is a meeting point of experiences in the lives of clients and the policy process of the organization, daily practice is more stubborn. Inspired by our former study concerning client councils in elderly care, we used Habermas’ theory of lifeworld and system world to take a closer look at the involvement of people with intellectual disabilities in the client councils. Although the organization put a lot of effort into the participation of their clients in the councils, there were limitations to the involvement of clients in this policy making process. The concept of colonization of the lifeworld (Habermas) was helpful to understand why experiential knowledge and stories were not equally valued as expert knowledge in the system world. The system world created a realm of distance, valuing scientific knowledge and abstractions, which led to an asymmetry of knowledge in the organization. We illustrated in our study the role of communicative action and its limitations.

We also describe what happened in daily practice, when we tried to further the emergence of open spaces by using the PARTNER approach in a day care centre that provides meaningful activities and care for people with physical disabilities and acquired brain injury. In these open spaces the experiential knowledge of patients was valued and merged with the knowledge and perspectives of professionals and management and new insights and mutual understanding evolved. We relate the open space to what Kunneman calls the interference zone. Kunneman argues that there is not a strict division between lifeworld and system, but that there is an interference zone, in which system and lifeworld are entangled and interfere. Within this zone, both logics and discourses constantly strive for priority, and constantly change context-bound formations. In order to understand what happened in everyday practice when we used the PARTNER approach to further the emergence of open spaces for patient participation, we interpreted our empirical findings by using the concept of culturalization introduced by Kunneman. This means that in the interference zone, the lifeworld can also influence the system via culturalization, as opposed to the colonization process that is described by Habermas. In our study we saw this culturalization process when clients, health care professionals and managers met as persons, felt remotivated, and experienced meaning. Here, an open space emerged, where all involved could learn from each other and were motivated to self- reflect, and started to behave differently.

In **chapter 4** we describe a case study in which we focused on the everyday practice of client councils in an organization for people with intellectual disabilities. We focused on our process of responsive evaluation and what we can learn from this, when we want to contribute to the values of social justice. Although responsive evaluation provides guidelines to include various stakeholders in dialogue, a substantial theory to understand power asymmetries and inequalities was lacking. In this chapter, we related our empirical findings on the participation of people with intellectual disabilities in policy making, and our own experiences with “doing participation”, to notions of social justice. We describe that in our search for a theoretical framework, the theory of Foucault on normalization turned out to be helpful. We

illustrate, that the engagement and striving for equality and social justice can turn out to be disciplining itself, when clients are invited to participate in a context, regulated by other's rules. Then there is the risk of being fitted into organizational structures, developed by professionals. The norms embedded in these structures are creating expectations on how to behave and what to do, but this may not be realistic for everyone, and can lead to alienation. These notions can contribute to our understanding of patient participation and our own participatory approach of responsive evaluation.

In **reflection II I**, Susan, describe how I started to reflect on the way patients and clients were involved in the everyday context of policy practices. Also, I started to reflect on the way we as researchers tried to involve clients in our own everyday practice. Were clients able to bring to the fore what is important to them within the frameworks of organizations (including our own)? Could they have an authentic contribution or did they have to fit into these frameworks? And how did this relate to social justice? I began to doubt and question the taken for granted, I started to reflect and find answers; how could we “do participation” in a good way and what does that mean?

## **PART B**

This part of the thesis relates to a responsive evaluation study, in which the perspectives and experiences of patients (people with aphasia) on participation are explored, in the context of rehabilitation health care and support. This research was commissioned by a patient organization, the Dutch Association for Acquired Brain Injury. It was assumed that more informed understanding of perspectives of patients and their experiential knowledge might help to better attune care to their needs, preferences and wishes and that this could also underline the importance of care and support to health care insurance companies, in the context of financial cutbacks in health care.

The aim of this study was to understand the value and meaning of aphasia centers from the perspectives of people with aphasia and their relatives. Aphasia centers provide care and support after the rehabilitation phase. These centers can be seen as a bridge between rehabilitation and society, and aim to support people with aphasia and their relatives in societal participation. We explored how aphasia centers can contribute to building a meaningful life with aphasia in the chronic phase, and how the centers can support clients to participate. Hence, this study also contributes to the understanding of the ambiguous concept of participation and its meaning, by exploring this meaning from the experiential knowledge and perspectives of people with aphasia themselves.

In the case study in **chapter 5** we present the findings of this study. From these findings we derived, that the support and care provided in the aphasia centers is highly valued by people with aphasia and their relatives. Aphasia centers were a first step to overcome isolation, and offered a first step towards participation in itself. The centers under study contributed to overcome barriers, to relate to others by building self-confidence and overcome shame. This was a big step stone towards participation in the context outside the center. From the perspectives of clients and relatives, the value and meaning of participation was linked to the concept of being and belonging. At the same time, people with aphasia found it hard to

meet societal norms of participation, framed as paid work, independency and self-reliance. It was hard to step out of the safe space of the center, because the external environment was fast, hectic and demanding for people with aphasia. Seen from a societal context and the associated norms of participation aphasia centers have become even more important.

As described in chapter 5, we used a responsive evaluation approach during our study. We were driven by normative arguments to include the experiences and perspectives of patients themselves, and to explore what they valued in the support they received. Working together with people with aphasia, who often did not have the ability to express themselves easily in a verbal way, was challenging during our research. It made us reflect on our own norms and frameworks in our work and in the scientific field. In **reflection III and IV I**, Susan, describe what I experienced while “doing participation” in this context. I became aware of the dominance of verbal accounts and information, and verbally orientated quality procedures within the scientific frameworks. I also experienced that it was difficult to bring to the fore the valuable knowledge and lessons we learned during our study; what to do with non-verbal accounts, relation orientated values, and information that is not well-defined or easy to measure? At the same time, I felt an urge to bring this valuable, often silenced knowledge into the scientific field, because I wanted to raise awareness for the perspectives and experiential knowledge of patients, in this study people with aphasia. It made me learn about my own normative position as a researcher in this field. Becoming aware of these power dynamics in “doing participation”, contributed to learning about what it implies when we aim to further the emergence of open spaces for patient participation, from a moral horizon of social inclusion.

## **PART C**

This part of the thesis is about patient participation in the context of research. Under the influence of the disability movement, the role of people with disabilities in research is shifting from a passive role, to a more active one. With the slogan: “nothing about us, without us” this movement clarified that people with disabilities didn’t want to be studied as objects, but that they wanted to be part of research itself as an active agent. This has led to the development of more emancipatory and inclusive forms of research, in which people with disabilities themselves become co-researchers or even principle investigators. Besides normative arguments for involvement (empowerment, democratic decision-making, equality and inclusion), it is assumed that this will lead to better insights in the perspective and lifeworld of people with disabilities.

In **chapter 6** we present a case study, in which we describe our own learning experiences with inclusive research, while working together with people with intellectual disabilities. The article is an auto-ethnographical study, in which we reflect on what we experienced along the way, and on the lessons learned about “doing participation” within our own everyday practice of research. In this study we explored the power dynamics in our team, the challenges we encountered, and the value of our collaboration. We bring to the fore that we experienced it as paralyzing to strive for equal tasks, roles and responsibilities in all aspects of the research process. We were equal, but not the same. We learned that it was helpful to



acknowledge differences; striving for sameness created an impasse, room for difference helped us to jointly find new ways to maximize participation. Ways we could not have envisioned due to our limited ideas of participation as being and doing the same (tasks, roles, responsibilities etc.). Acknowledging differences and uniqueness enriched our research outcomes and made us reflect on our own, sometimes rigid, academic framework. Participation is always a two-way affair of people who participate, and is embedded and influenced by an environment that can be more or less (dis)enabling. Becoming aware of this relational dynamic and the influence of the context opened new spaces for mutual understanding, so long as we were willing to reflect on our taken for granted position. Within this open space we worked together with others who had different viewpoints, different values and different strengths and weaknesses (including ourselves). At the same time, within this relational and contextual complexity, we have become more aware of our own position, our own power and the boundaries of our tight frameworks.

In part C we present **reflection V** in which I, Susan describe what we experienced when we shared our reflections and findings as described in chapter 6 with the members of the project group (professionals from a health care organization, relatives, professional coaches of an advocacy group and scientists). It is about the relational complexity and the power dynamics we encountered while “doing participation” in this particular context; we describe how we entered “the avoided place” and the learning potential it generated about the emergence of open spaces for patient participation. We wanted to control the situation and thought over and over again about solutions to fix the difficult, tensed situation. Simultaneously, we learned that participation cannot be controlled and fixed; participation is precarious and untamed.

In the final chapter of this thesis (**chapter 7, the general discussion**) we describe our main findings, and what we have gradually discovered during our explorative journey through the landscape of patient participation in health care and research practices (the case studies), while “doing participation” ourselves (auto-ethnographical reflections). Furthermore, we work towards an answer to our guiding research question: *How to further the emergence of open spaces in health care institutions with participatory approaches and what is the importance of such open spaces for patient participation and inclusion?*

We start by describing the different meanings and perspectives of patient participation within everyday health care and research practices. Although participation has different meanings for different people, in different social positions, and relates to various interests and values, the meaning of participation is often taken for granted and hardly discussed. We also focus on what happens when different meanings start to interact: what happens when we try to further the emergence of open spaces in which all involved can have a say and in which different meanings can come together and can be shared? We conclude that it takes effort to involve patients, because their meanings, perspectives and experiential knowledge do not come to the fore naturally. In our terminology: there is a need to work towards the emergence of open spaces, in which all voices can be articulated and heard, when we aim for the flourishing of patient participation.

We continue by describing that we gradually discovered the role of power, related to the emergence of an open space for patient participation. This relates to questions about who invites to participate and who

is invited, what the frameworks for participation are, and what kind of knowledge is valued. Also, we as researchers with a participatory approach, were entangled in power dynamics ourselves. Along the way we have become increasingly aware of the moral and existential complexities of patient participation, how this relates to power, to our own involvement and the challenges that we faced on our way. This means that power always interferes with open spaces, and can either limit or positively contribute to the dialogue and inclusion of patients' voices. The emergence of open spaces is important for fostering patient participation and inclusion, because the power dynamics can lead to boundaries for the experiential knowledge of patients within the open space. We learned that we need to reflexively work with power, including our own power, in order to further the emergence of open spaces for patient participation.

What we discovered also has implications for responsive evaluation and other participatory action research approaches, that acknowledge relational complexity. As researchers with a participatory approach, we are entangled in power relations ourselves. It was exactly this relating to, and working with patients itself along the way, that made us reflect on our own taken for granted frameworks, guidelines and our own normative position as researchers. This normative position is connected to power.

We learned that the supposed open spaces are power-full spaces and that more is needed than only fostering the emergent creation of an open space by dialogue. We have experienced the value of enduring and working through the messy, power-full relational complexity of those power-full spaces. This brought us to the so called "swampy lowlands", a term borrowed from Donald Schön, in which we were confronted with moral and existential questions (Kunneman calls them "slow questions") about in- and exclusion, while exploring patient participation. Although it was not easy and often took courage to enter the "avoided place", we experienced that it is exactly here that we learned most about patient participation and social inclusion. Surprisingly it is entering the "avoided place" that brought to the fore the most valuable lessons, because here a process of mutual learning emerged, and brought to the fore new insights.

We conclude that it is not enough to strive for the creation of an open space, in which all involved can have a say. Working from a responsive research approach takes effort and courage, to connect the different perspectives and meanings within a power-full space, including our own. Especially within the current frameworks of science. Science is about knowledge and about "truth". Working from a participatory research approach is also about us as researchers, and what we ourselves contribute to this knowledge system. As researchers we are not outside the production of knowledge, but we are part of it. We "are" the knowledge system up to a point. This means that we must question our own frameworks and our own acting, and how these relate to power dynamics, as we did in our own research projects (the reflections). How do we include the experiences and perspectives of patients and clients? What do we exclude? What is our effort to do justice to these perspectives, value different kinds of knowledge, and strive for its inclusion? How can we work in the power-full spaces, what are openings and boundaries for silenced knowledge? And what does that imply for ourselves?

It made us realize that patient participation is not about professionals and researchers, inviting patients within the frameworks in everyday practice, while giving them a voice and empower them. Participation is first and foremost about how we as professionals and researchers relate and connect to

patients, the courage to become entangled ourselves, and start reflecting on our own normative position that relates to power and knowledge. This sometimes requires “free speech” (parrhesia), when something is at stake that really affects us and that puts under pressure what we stand for and value. It is from within the power-full space of “doing participation” that we learned about how this power relates to openings and boundaries for valuable silenced knowledge. We found out that we had to put an effort and put an interest in stretching the boundaries of the power-full spaces of participation; we learned that we can use our power positively, by being interested in the experiences and perspectives of patients themselves and by putting an interest in opening up the power-full space for often silenced knowledge from a moral horizon of inclusion, in order to contribute to good care and good life.

The explorative journey through the landscape of patient participation has generated many new questions along the way. In the final part of this chapter, we describe future directions and pathways to discover more about patient participation, and how we can contribute to the emergence of open spaces in health care institutions. These new pathways relate to questions about breaking boundaries and opening up for valuable silenced knowledge (for instance via arts-based research approaches), questions how to put an interest in often silenced existential and moral learning processes within organizations, as complementary form of learning to cognitive learning processes in order to contribute to social inclusion (modus 3 learning), and questions relating to learning about co-creation and organizational change to come to good care and a good life for all involved. Exploring these pathways in a participatory way will enrich the findings and bring new insights.